Schmieding /ILC Solutions Forum on Elder Caregiving

June 2, 2005 ♦ 9 am -12 noon

Schmieding Conference on Elder Homecare

June 2, 2005 ♦ 12 noon - 4 pm

REPORT OF FINDINGS

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FEDERAL BARRIERS TO PROVIDING IN-HOME ELDERCARE

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SOLUTIONS FOR KEEPING ELDERS AT HOME FOR LIFE

TESTIMONY OF ELIZABETH MACDONALD TO THE POLICY COMMITTEE OF THE WHITE HOUSE CONFERENCE ON AGING

Elizabeth MacDonald serves as Legislative Assistant to U.S. Senator Blanche Lincoln of Arkansas where she is her chief policy advisor on health care for the Senate Finance Committee and the Senate Special Committee on Aging. Elizabeth served as the Senator's principal consultant and negotiator on the *Medicare Prescription Drug, Improvement, and Modernization Act of 2003*. She has also advised the Senator on Medicaid, the State Children's Health Insurance Program, and welfare reform. Elizabeth received a master's degree in public administration from George Mason University and graduated from Washington College magna cum laude with a B.A. in English.

SUMMARY OF FINDINGS

As the first of the 77 million Baby Boomers turn 65 years old in 2011, what kind of long term care will they demand? Undoubtedly, most seniors would rather receive care in their homes than in nursing homes. Despite this public demand, there are many federal barriers to providing in-home eldercare. Unfortunately, the Medicare and Medicaid programs are both structured in ways that hinder eldercare at home.

The Medicare home health benefit is intended for beneficiaries who need acute, skilled medical care, not for those who need non-medical supportive care or personal care assistance required by chronically ill individuals. However, the *Medicare Prescription Drug, Improvement, and Modernization Act of 2003* (MMA) created two Medicare home health demonstration projects. One liberalizes the "homebound" definition for certain chronically disabled Medicare beneficiaries so that they can continue receiving care at home rather than in nursing homes. The other demonstration seeks to provide Medicare beneficiaries with a new option of receiving home health services in an adult day setting. Senator Lincoln also supports the Program of All-inclusive Care for the Elderly (PACE), a unique model of care serving chronically ill seniors while maintaining their independence in their homes for as long as possible. Senator Lincoln has sponsored legislation (S. 1067) to expand PACE to rural areas.

Medicaid is biased towards institutional care, but most states have used Medicaid Home and Community-Based Services (HCBS) waivers to help seniors receive care at home or in the community rather than in nursing homes. Senator Lincoln is proud that Arkansas has utilized the HCBS waiver program as well as the Medicaid 1115 waiver program in an effort to keep elders at home. Some proposals that seek to expand states' ability to provide these services include the Real Choice Systems Change grants under President Bush's New Freedom Initiative, the Money Follows the Person Act of 2005 (S. 528), and initiatives creating new Medicaid plan options for HCBS.

Knowing that public resources will be unable to fund the substantial amount of long term care that the Baby Boomers will require and that most Baby Boomers will want to age at home, Senator Lincoln believes that Americans should prepare now by investing in a private long term care policy. To help Americans afford long term care and encourage Baby Boomers to plan ahead for their long term care needs, Senator Lincoln will soon introduce legislation to create a tax credit for caregivers and individuals faced with the immediate expense of long term care and a tax deduction to help consumers pay long term care insurance premiums.

Complicating matters is the federal budget. Senator Lincoln believes that the current effort in Congress to cut $10 billion from the Medicaid program will only hinder federal and state efforts to help seniors receive home and community-based care.

RECOMMENDATIONS AND REFORMS

MEDICARE

Home Health Care

Medicare, the nationwide health insurance program for the elderly and individuals with disabilities, pays for care in the home as long as the beneficiary is "homebound," in need of skilled care on an intermittent basis, and under the care of a physician. Under the home health prospective payment system (PPS), Medicare makes a payment for every 60-day episode of care that an eligible beneficiary receives. While the home health benefit is important for beneficiaries, it is not a long-term care program. Medicare pays for home health care only if the care is medically reasonable and necessary for the treatment of illness or injury. Although a beneficiary may receive an unlimited number of home health visits under Medicare, services must be provided pursuant to a plan of care that is prescribed and periodically reviewed by a physician. Such care must be re-certified by a physician every 60 days. Medicare's home health benefit is intended for beneficiaries who need acute, skilled medical care, not for those who need non-medical supportive care or personal care assistance required by chronically ill individuals.

Federal Initiatives to Eliminate Barriers to In-home Eldercare in Medicare

Home Health Care Demonstration Projects

In the *Medicare Prescription Drug, Improvement, and Modernization Act of 2003* (MMA), Congress created two home health demonstration projects. The Home Health Independence Demonstration studies the benefits and costs of providing needed home healthcare services to Medicare beneficiaries with severe, chronic conditions who would not otherwise be deemed "homebound" under the usual Medicare rules. This demonstration allows an eligible beneficiary with a permanent and severe disabling condition to leave home for as often and as long as she likes (except to work outside the home) and still be considered "homebound" and receive Medicare home health services. The demonstration began in October 2004 and will run until October 2006 in three states (Colorado, Massachusetts, and Missouri). Liberalizing the "homebound" definition for certain chronically disabled Medicare beneficiaries will allow them to receive care at home rather than in a nursing home.

The Demonstration Project for Medical Adult Day Care services allows a home health agency, directly or under arrangement with a medical adult day care facility, to provide medical adult day care services to substitute for a portion of home health services otherwise provided in a beneficiary's home. The demonstration will be for three years in not more than five sites. This demonstration was based on a provision in Senator Lincoln's legislation (S. 1238 in the 108th Congress) that sought to provide Medicare beneficiaries with a new option of receiving home health services in an adult day setting. Because adult day centers provide care all day, they enable family caregivers to continue working or simply take a break from their care-giving duties. More than 22 million families nationwide (or nearly 1 in 4 families) serve as caregivers for aging seniors, providing close to 80% of the care to individuals requiring long-term care. The services offered in adult day care facilities provide continuity of care and an important sense of community for both the senior and the caregiver, while allowing the senior to continue living at home. The Center for Medicare and Medicaid Services (CMS) will implement the demonstration later this year.

Community Option for Rural Elders (CORE) Act

Senators Lincoln and Brownback recently introduced the Community Option for Rural Elders (CORE) Act (S. 1067). The objective of the CORE Act is to provide frail elders in rural areas greater access to community-based services as an alternative to permanent nursing home placement. Specifically, the CORE Act would provide much needed support for the development of Programs of All-inclusive Care for the Elderly (PACE) in rural areas. PACE organizations currently provide eligible beneficiaries with a comprehensive, fully integrated package of Medicare and Medicaid covered services, as well as services not covered by these programs. The purpose of PACE organizations is to maximize individuals' functional capacity, thus supporting their ability to continue to live in their homes and communities. To date, these organizations have been developed to serve urban areas. The CORE Act would expand access to PACE services to individuals living in rural areas.

The CORE Act would authorize the U.S. Secretary of Health and Human Services to give PACE organizations the operational flexibility they need to respond to the realities of providing health care in rural communities by waiving specific current PACE statutory and regulatory requirements. That flexibility would neither compromise the quality of care for which PACE organizations are known nor jeopardize the cost-effectiveness of PACE services to Medicare and Medicaid. It would encourage innovation to provide quality health care to individuals so they are able to stay in their homes and communities. In addition, the CORE Act would authorize start-up and development funding as well as technical assistance to States and providers. The CORE Act has been referred to the Senate Finance Committee for further consideration.

MEDICAID

Medicaid provides comprehensive acute and long term care benefits, but states have been working to increase the number of services and supports in the community to facilitate independent living for seniors and individuals with disabilities. This is due, in part, to the 1999 Supreme Court ruling in *Olmstead v. L.C.*, which said that states must provide services in the most integrated setting appropriate to the needs of individuals with disabilities.

Home and Community-Based Services

The principle way states provide home and community-based services is through Medicaid Home and Community-Based Services (HCBS) waivers. The Medicaid HCBS Waiver program, which was signed into law in 1981 under section 1915(c) of the Social Security Act, allows states the

option of providing home and community-based care through Medicaid as long as it does not cost more than institutional care. In essence, the HCBS program allows states to waive certain provisions of the Medicaid statute: "statewideness," comparability, and the community income and resource rules for the medically needy.

Presently, all states except Arizona have Medicaid HCBS waivers to provide a variety of home and community-based services to individuals who would otherwise live in institutions. The services provided vary from state to state but could include personal assistance, respite, and home modifications. It varies greatly between the states, but on average the federal government covers 57% of the cost of Medicaid home and community-based services; the remainder is covered by the states.

Arkansas Initiatives to Eliminate Barriers to In-home Eldercare in Medicaid

Senator Lincoln is proud that the Arkansas Division of Aging and Adult Services has developed a number of home and community-based programs so that elders can choose how and where they receive long-term care services. Four programs currently operating in Arkansas were established through the Medicaid 1115 Waiver Research and Demonstration Program and the Medicaid HCBS Waiver program. (Section 1115 of the Social Security Act permits the Secretary of Health and Human Services to waive certain portions of the federal Medicaid statute for a five-year demonstration project, if the demonstration is budget neutral to the federal government.)

IndependentChoices (Cash and Counseling)

In 1998, Arkansas partnered with the Robert Wood Johnson Foundation and received an 1115 research and demonstration waiver from Centers for Medicare and Medicaid Services in order to initiate IndependentChoices, a program to provide people with disabilities with more options and greater personal autonomy in determining how best to meet their personal care needs in a cost effective manner. Consumers who participate in the program receive a monthly budget based on his/her needs. They can use this money to hire personal assistant services, make home modifications, and more. Counselors work with consumers to develop and revise individual budgets. In addition, consumers have the option of appointing a representative, and being part of a peer support group. So far, Arkansas has served over 3,500 through this program. Program evaluations of the IndependentChoices program have been positive, showing that participants receive a higher quality of care than they would through agency services and that participants have a high level of satisfaction with the care they receive. Arkansas' demonstration program was so successful that the U.S. Department of Health and Human Services adopted it as the model for their Independence Plus initiative.

ElderChoices

ElderChoices is Arkansas' Medicaid HCBS waiver designed for its elderly population and has been in operation since 1991. ElderChoices is designed for persons who are nursing home eligible due to physical, cognitive or medical reasons. The program is designed to assist elderly persons reside in their own homes, or live with relatives or caregivers for as long as possible, if that is their choice. ElderChoices provides a variety of services including home management services, such as laundry, essential shopping, heavy cleaning, and yard work. It also provides home delivered meal services, adult day care, adult day health care, a 24-hour emergency response system, and respite. This program has provided services to more than 20,000 elderly Arkansans since 1991. There are

currently 5,865 recipients participating in the program with a statewide total of 291 providers of service.

Alternatives

This program, another Medicaid HBCS waiver in place since 2000, allows adults with physical disabilities to avoid institutionalization by allowing them to hire and manage their own attendants and modify their homes to make them accessible for wheelchairs.

Affordable Assisted Living

Assisted living is a licensed setting that combines housing, services and health care to meet the scheduled and unscheduled needs of residents 24 hours a day. In January 2003, Arkansas licensed its first affordable assisted living facility, The Gardens at Osage Terrace in Bentonville. The Gardens, in accordance with state licensure requirements, provides individual rooms, private baths, individual climate controls and kitchenettes for its residents, making it an attractive alternative to nursing homes. Because the Medicaid rates for affordable assisted living are about half the cost of nursing homes, the program saves both the state and federal government money. The Medicaid HCBS waiver pays for the services the senior receives while in the facility.

Federal Initiatives to Eliminate Barriers to In-home Eldercare in Medicaid

The New Freedom Initiative

In 2001, the Bush Administration proposed The New Freedom Initiative with the goal of increasing the ability of seniors and individuals with disabilities to live in a home or community-based setting. The New Freedom Initiative includes many components, including Money Follows the Person and Real Choice Systems Change grants.

The Money Follows the Person Demonstration would help states in developing and implementing a strategy for rebalancing their long-term care systems to introduce more cost-effective choices between institutional and community options. The President's FY2006 budget proposes a five-year demonstration project that would be 100% funded by the federal government for the first year. After this initial year, states would be responsible for matching payments at their usual Medicaid matching rate. In March, Senator Harkin and Senator Smith introduced the Money Follows the Person Act of 2005 (S. 528), a bill to authorize the Secretary of Health and Human Services to provide grants to States to conduct demonstration projects that are designed to enable Medicaid-eligible individuals to receive support for appropriate and necessary long term services in the settings of their choice.

The Real Choice Systems Change grants promote the goal of community living for individuals with disabilities and long-term illnesses. Since fiscal year 2001, Congress has appropriated over $200 million for the Real Choice Systems Change (RCSC) Grants for Community Living. In implementing the RCSC program, CMS has awarded over 200 grants to all fifty states, the District of Columbia (DC), and two territories totaling approximately $188 million. States and other eligible organizations, in partnership with their disability and aging communities receive grants to design and implement changes that will result in effective and enduring improvements in community long-term support systems.

Creating a Medicaid Option for HCBS/Reforming Long Term Care in Medicaid

Some have called for Congress to amend the Medicaid statute to establish a state plan option for HCBS services. The federal government mandates coverage for institutional facilities like nursing

homes and home health services, but allows states, at their option, to cover home and community-based services through the Medicaid HCBS Waiver program as long as the cost of services under a waiver in addition to other state Medicaid services is cheaper than what would have been spent on institutional care. Because individuals are not entitled to HCBS waiver services the way they are to mandatory services under Medicaid, many people who want waiver services must wait to get them. The demand exceeds the availability in most states, and only some states keep waiting lists at all. According to the General Accountability Office, waiting lists can evolve because waivers allow states to cap their overall expenditures. States are not allowed to cap their spending in the traditional Medicaid program. Some argue that removing the requirement for a waiver and establishing a state plan option for HCBS services would also reduce a time-consuming, burdensome process for states and provide them with greater flexibility.

Others argue that Congress should change the mandatory nursing home coverage in Medicaid to a state plan option that covers comprehensive long-term care services, and then allow states the flexibility to define that coverage. In such an option, they argue, home and community-based services should be the primary form of service, and nursing homes should be the last resort.

PRIVATE LONG TERM CARE INSURANCE

Almost one-third of Medicaid costs can be attributed to long term care of the elderly and disabled. Senator Lincoln believes that we need the Baby Boomers to prepare for their futures now by investing in a private long term care policy. Many Americans simply do not know that many long term care services are not covered by private health insurance or by Medicare. Historically, long term care costs have been paid first by families out-of-pocket and then by Medicaid for those who qualify and "spend down" to the income and assets limits. Undoubtedly, many Baby Boomers will be disappointed to discover that Medicaid's current bias towards institutional-based care may prevent them from aging at home.

To help Americans afford long term care and encourage Baby Boomers to plan ahead, Senator Lincoln is going to introduce legislation called the Long Term Care and Retirement Security Act with Senator Grassley to create a tax credit for caregivers and individuals faced with the immediate expense of long-term care. The bill would also help Americans better prepare for their future needs by providing a tax deduction to help consumers pay long-term care insurance premiums for policies that meet strong consumer protection standards. Such plans will cover both medical and non-medical supportive care and personal care assistance so that elders can age at home.

Unless we encourage Americans to plan ahead, demand and costs for long term care services could deplete their savings and exhaust government programs. Senator Lincoln's tax incentives are a good first step forward to avoiding this problem.

CURRENT BUDGETARY CLIMATE/CONCLUSIONS

Public resources will be unable to fund the substantial amount of long term care that the 77 million Baby Boomers will require. Whether Congress chooses to amend Medicare and Medicaid and/or enact tax incentives will depend on budget priorities and political pressure, undoubtedly influenced by the fact that the changing demographics in our country will create an increased demand for long term care. Congressional action may also depend largely on what type of care –

institutional or community-based – the aging Baby Boomers will demand. Will legislators and government executives listen to this politically powerful group?

Currently, Congress, encouraged by President Bush, is faced with cutting $10 billion from the Medicaid program. The budget resolution passed by Congress directs the Senate Finance Committee to report out savings of $10 billion over five years from programs under its jurisdiction. Medicaid is expected to be the source for a large portion of that savings, which could prove detrimental to those who rely on it for health care and long term care services. The reality of the situation is that Medicaid has become our nation's de facto long term care system, so any budget cuts will have a tremendous impact on our states and on our nation's seniors. Senator Lincoln believes that removing federal resources from the Medicaid program will only hinder federal and state efforts to help seniors receive home and community-based care.